Summary of ECD Global Alliance Internet Chat
02 May 2015

5 Attendees

- A member, who lives in Houston, was thanked for all his efforts towards the ECD convention later this year. He gave the credit to his wife, who is "a dynamo"! This member has recently lost 10lbs. He says that it is due to "brutal" dieting. 1000 calories a day or less!! He was congratulated. Another member said that she wanted to make disciplined healthy choices, but she seems to keep on eating "those chocolate bars".

- A member who is on one of the vemurafenib (V) trials is thinking about coming off it, but still getting V as an off-label drug. He is from Minnesota and he is using a lot of time/money to travel to NY monthly. He is moving to San Diego with June as the target month.
  When he moves to SD, he won't be able to justify the cost of traveling to NY any more. He is glad that Dr. Kurzrock is right there, because he needs to find a doctor who will administer the drug and is local. Dr. Kurzrock's team, in San Diego, are interested in trying to help and he is seeing her in June. His present dose is 3 in the morning and 3 in the evening, but he thinks that he "could probably live with 2+2", or even 2+1.
  He needs someone who has the passion to keep ECD patients in check, and monitor their health on an ongoing basis. He thinks that clinical trials are great, but there is too much focus on using the trial drug, and not enough looking to the longer term.

- The other member on V is taking 2 and 2. His side-effects are the same, but became less severe when the dose was reduced. He is on the clinical trial run by Dr. Janku at MD Anderson, and has been on V for a bit more than a year. He is stable ("whatever that means"). His study coordinator had the radiologist re-examine his MRI's and he learned that the main lesion (a tumor on his heart) is slowly getting smaller.

- The ECDGA is hoping Dr. Kurzrock will be able to attend the convention in Houston, but she has some conflicts. She may be able to make the last day of the Patient Gathering, but probably not the Medical Symposium itself.

- One member on V asked the other about long term planning. He had not discussed this as yet, as he remains on the trial for the foreseeable future. Things are changing so fast that he hasn't thought what the long term will bring. He is still getting symptoms from the ECD and side effects from V, too. He thinks that his ECD symptoms are much less severe than most, maybe because he was diagnosed early (about 2010). He gets hand foot syndrome (this is basically reduced sensation in the

fingers and pain in the feet). He had lots of skin cancer lesions at first, when he was on 4 and 4. This has improved tremendously; partly, he believes, because they have reduced his dosage.

- The other member on V has hand & foot syndrome and rashes. He was diagnosed in 2014.
  He had a lot of problems with his eyes including bulging, pink eyes, red eyes, double vision, etc. A lot of these have gone, but not his eye sensitivity, which could also be from the V. So at times, "it's confusing whether it's ECD or the drug!"

- A member came on whose sister is very ill with ECD, and who has been having great difficulty in getting approval of treatments. She told us that she had great news. She has been able to get Interferon, for her sister, approved for the next 6 months. She is about to start Pegylated Interferon, weekly.
  Because of the difficulties getting interferon, she had been working on a "back up plan". This involved the drug company Merck, and a new drug that they are testing called ACT. She had a lot of praise for the help she had received from the ECDGA and the ECDGA website. Also, there was a relevant article in the New York Times recently. Her sister is BRAF negative and so can't take V.

- We were told that another drug company, Genentech, has a similar program to that of Merck, to help patients get access to medicines. It is called "Patient Access Solutions".